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ABSTRACT

Identification of retardation or other handicaps at birth occurs when parents are most vulnerable. Such a situation is complicated and hazardous; and parents react with shock, disbelief, intense grief, guilt, and anger. Furthermore, siblings do not escape the trauma, and are frequently bitterly resentful of the family's situation, guilty at their rage, and fearful that they themselves may be defective or tainted. Families may disintegrate under this kind of pressure without a support system. The five R's of family life which parents of handicapped children should consider and utilize are regularity, routine, repetition, relaxation, and reinforcement. (Author/SBH)

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Survival Skills for Exceptional Parents

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by

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Abstract

The birth of a child is usually an occasion of joy and relief. Parents view their children as extensions of themselves and, therefore, anticipate only that the child will be as "normal" as they are.

Identification of retardation or other handicaps at birth, then occurs when parents are most vulnerable. Such a situation is complicated and hazardous. Parents react with shock, disbelief, intense grief, guilt, and anger. Furthermore, brothers and sisters do not escape the trauma. They are frequently bitterly resentful of the family's situation, guilty at their rage, and fearful that they themselves may be defective or tainted. Families may disintergrate under this kind of pressure without a support system.

The Five R's of family life - Regularity, Routine, Repetition, Relaxation, Reinforcement - are presented for parent's consideration and utilization.

Survival Skills for Exceptional Parents

Two years ago I was returning from Ireland to London by Brit Rail when a family group joined me in South Wales. I perceived at once that the young lady of perhaps twenty was exceptional. Her mother and grandmother spoke not a word to her after settling in the compartment so she and I exchanged smiles, and caught the thistle down pompons as they floated through the window. I complimented her on her straw sandals, telling her that was the latest style in the United States. Finally the mother dropped her keys and both she and I bent over to retrieve them.

"I teach exceptional children in the United States. How old is your daughter?" I asked softly. It was like a flood gate opening. "Did you hear, Grandmere? This lady teaches exceptional children in the United States," the mama all but shouted! I joined them for tea, we exchanged family snapshots, and when London was called out, they all but spilled out with me - waving and shouting, "Don't forget - come see us on your next holiday!" What a dramatic change when the pressure was removed from that mother. Immediately the defensive and defeatist attitude melted. And that's what I want to share with you from a personal viewpoint - Taking the pressure off parents.

The birth of a child is usually an occasion of joy and relief. Parents view their children as extensions of themselves and, therefore, anticipate only that the child will be as "normal" as they are (Burton, 1974).

The identification of retardation or other handicaps at birth, then, occurs when parents are most vulnerable (Jordan, 1972).

Such a situation is complicated and hazardous. Parents react with shock, disbelief, intense grief, guilt and anger. Wolfensburger (1967), describes these various emotions as: Alarm, ambivalence, anger, anguish, anxiety, avoidance, bewilderment, bitterness, catastrophic reaction, confusion, disbelief, disassociation, embarassment, envy, fear, financial worries, grief, quiet, helplessness, identification, immobility, impulses to destroy the child, lethargy, mourning, overidentification, pain, projection, puzzlement, regret, rejection, remorse, self-blame, self-pity, shame, shock, sorrow, suicidal impulses, trauma, etc.

Brothers and sisters of retarded children do not escape the trauma. Grossman (1972) reports that brothers and sisters are frequently bitterly resentful of the family's situation, guilty about their rage at their parents and at the retarded sibling, fearful that they themselves may be defective or tainted. The closer the brother or sisters' age is to the retarded child, the more he or she is affected in personality and social destiny (Farber, 1968). Moreover, siblings are sometimes deprived of the time and resources they need to develop because every support the family has to give is used in the care of the handicapped child.

Parents often come to feel virtually imprisoned by a handicapped child. Nerves become frayed. Anger, panic, self-lacerating guilt or recrimination shatter parental dreams and fragment family resources. Families may disintergrate under this kind of pressure (Brutten, Mangel, and Richardson, 1973).

As I've communicated with parents throughout our Southland, two crucial concerns always surface. (1) What will happen to my child when the props are removed and I am no longer around to take care of him?

(2) The inordinate amount of grief and guilt that parents, especially mothers, absorb from society at having brought a child like this into the world. Society all but screams, "It's your fault! Why can't you fix him, make him behave, or why con't you discipline him?" Meanwhile, there are always an abundance of do-gooders telling perents, "Don't worry: this will all work out!" And that's an insult to parental sensibilities. Furthermore, it can cause as many burnouts as the guilt route.

I have learned one important lesson from my parents. Namely, the twenty-four-hour, seven-days-a-week reality test has standards far higher than any exam I ever took while pursuing any degree.

How can we lessen the loneliness and fatigue of parents as they respond endlessly to a crisis which is chronic? How can we provide crucial assistance to other members of the family so they can function adequately?

When family members ask, "What can I do to help?", I tell them among other things: You can make mealtime, bedtime, a drive in the car, a trip to the supermarket, and any ordinary household activity into meaningful teaching situations. Remedial principles can be utilized to help a child learn to do household tasks. Parents who take the time and trouble to teach systematically some of the skills involved in cooking, shopping, cleaning, gardening create an ideal opportunity to develop logic, system, and arithmetic to their children.

Perhaps even more important, these tasks give the child a feeling of importance and self worth, a sense of belonging and contributing to the family. Teaching household tasks to your handicapped children will be your best insurance against their "Learned Helplessness."

My parent-sharing sessions revolve around the five R's of Family Life - Routine, Regularity, Repetition, Relaxation, and Reinforcement.

Routine and regularity provide a predictable, consistent, and orderly environment for a child. He knows what to expect and when to expect it. Don't turn a child loose to stumble by himself. Explicit, predictable responses to daily events by parents help the child to internalize order and become more predictable himself.

Establishing limits and stating consequences clearly until they are understood anchor the child to the real world. Children continually test their parents' firmness. Parents have a right not to be nagged and conjoled constantly when thay have given "no" for an answer provided they have given a reasonable explanation for their action and their child has had a reasonable opportunity to question it (Viscott, 1976).

Habit training from the earliest days will stand the child in good stead when there's no one around to offer direction.

Dr. Claudia Anderson (1972), noted psychiatrist and mother of a MBD daughter states with authority, "What this child does not have in his head, he had better have in his habits... or in the purse of family concern. The really unfortunate ones are those who have not received the habit training early in life that will help to make them acceptable members of society."

Repetition is the third R. This child often "forgets to remember." His hear-absorb-react cycle is slower. It takes him longer to learn to get meaning from looking, listening, touching, moving. Longer to learn to intergrate information from two or more senses, longer to

remember what he's seen, heard, felt, or done, longer to follow directions. Tell a child often how, when, where, why-but not all at once. Requests should be reasonable and sparse, short and simple, and related to the task at hand, not some distant one. Don't clutter speech with verboseness. Be firm, gentle, speak slowly, clearly-never talking down to a child, never angry, impatient, or shrill of voice. Parental behavior is contagious.

One of the missing ingredients from many homes with handicapped children is relaxation. One night our daughter bolted in late for the evening meal-"Have I missed the laughing?" she wanted to know.

Laughter is the safety belt of the nervous system. Celebrate life-Enjoy each other. Hoard family jokes and jollies. Turn off the television. Play ball, run, jump, box a punching bag, make cookies or whatever with your child. Provide outlets for acceptable release of excess energy. This energy can't be bottled successfully or stored up. Above all, parents, take off time for good behavior. To say I can't afford a babysitter is foolish. You can't afford not to have one occasionally! Michael Bayley (1973), reporting some sensitive British studies, documented the effects of the daily grind on families who retained a handicapped member at home for many years. Interspersing daily routines with brief, intermittent absenses reduced the parent burnout and enhanced relationships for both parents and handicapped children.

Value yourself as a person. Accept your own strengths and weaknesses. Don't revolve your entire life pattern around a handicapped child. Spend time away from him. Send him to camp. Find a foster grandmother. Rebuild that husband-wife relationship. Don't loose your spouse to your handicapped child.

Dr. Leah Ziskin (1978) states, "It took years for me to realize I was more than the mother of a retarded child. When I decided that I did not want the major distinction of my life to be that I was the mother of a retarded child, I was finally able to pick up the pieces of my life and proceed."

The last R could be the most important - Reinforcement. Nothing will ever take the place of encouragement of a child's life, and encouragement, or positive reinforcement, begins in the crib. The air is so full of ego-defeating germs for the handicapped child. So often he sees himself as a "non-anythinger." Before we can ever teach a child to sit, stand, walk, or behave in appropriate ways, we must teach him to feel good about himself. Your child can accomplish only if you believe in him. Praise him for what he is. Don't dwell on his failures. Find his strengths and reinforce them. Accentuate the positive. One of my students, only 17, hanged himself in the psychiatric ward of a private hospital. His father, an outstanding surgeon had the same ambition for his cerebral palsied son.

Nothing gets in a child's way more than trying to be something he is not. So accept, accentuate, and build on what he is. Self esteem is the main string that slates every child for success or failure (Briggs, 1970). It is not the child who is taught about love but the child who has experienced love that grows into a healthy, happy well-adjusted adult.

The home is a classroom, a laboratory for life. No matter how much professional help a youngster is getting or how sympathetic the school is, the major part of long range goals is borne by the parents. Even though there are no purple hearts for parenthood, it takes a heap of love and hard work to be parents. I salute you.

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